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## **Every Child Matters outcomes: What do they mean for disabled children and young people?**

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# **Every Child Matters outcomes: What do they mean for disabled children and young people?**

## **Abstract**

To date, little attention has been paid to the appropriateness of the Every Child Matters outcomes framework to disabled children<sup>1</sup>. This paper reports findings from a research project which sought the views of disabled children and their parents about their desired outcomes. Twenty-nine children and 90 parents were interviewed. The findings indicate that ECM outcomes are appropriate to disabled children but can have different meanings. In addition, the need to recognise the importance of maintaining outcomes, as well as progress, is highlighted.

## **Introduction**

Policy in children's services now emphasises the importance of the outcomes achieved for individuals. There is recognition of the need to promote the well-being of children through outcomes-focused practices and assessment by social care and other support services. The development of the Looking after Children assessment and action records and the Framework for the Assessment of Children in Need (Department of Health, 2001) aimed to provide a systematic approach to assessment and promote the quality of care and attainment of developmental outcomes for children in need. The Every

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<sup>1</sup> For brevity, the term children is used to apply to children and young people up to 19.

Child Matters (ECM) outcomes framework for children - focusing on five outcomes of be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being - has become central to all policy for children (Department for Education and Skills, 2003). Similarly, the National Service Framework for Children, Young People and Maternity Services (NSF) (Department of Health/ Department for Education and Skills, 2004) emphasises the need for agencies to work together to achieve positive outcomes for children and young people.

Such policies provide a context within which agencies are expected to deliver services which achieve the best possible outcomes, aiming to ensure that the children most at risk of social exclusion have opportunities to build successful and independent lives.

Interpreting what the ECM outcomes might mean for disabled children can be difficult, as each of these dimensions may prove problematic when assessing the progress of different groups of disabled children in relation to normative development. For instance, how should we define 'achievement' for a child with a degenerative condition whose abilities are deteriorating, or 'being healthy' for a child with a life-limiting illness? These questions point to a more general concern about what the priorities for outcomes should be for children whose development and/or physical health is compromised, and how these children, and their parents, might define these priorities.

In the past, there has been some confusion about the meaning of the term outcomes. A number of writers have noted the importance of distinguishing between service activity and the impact of this activity on users and suggested that the term 'output' should be used for the former and 'outcome' for the latter (for example, Axford and Berry, 2005). Research with disabled and older adults and carers (Qureshi, 2001) identifies three types of outcomes: maintenance outcomes, for example maintaining acceptable levels of personal comfort; change outcomes, for example improving confidence, or ability to get about; and process outcomes, the results of the way in which services are provided, for example whether people feel valued and respected.

Whilst there is a body of literature on disabled children's views of services (for example, Connors and Stalker, 2003; Turner, 2003), there has been little investigation of their or their parents' views on the outcomes they aspire to achieve. The research reported here aimed to identify the outcomes disabled children wished to achieve from provision of support services and the outcomes their parents desired for them. The outcomes highlighted in policy cannot usually be achieved through input from one service, nor should they be confined to one setting, such as school. The study therefore focused on 'support services' in general rather than services from any one agency.

This paper summarises the results of the research under the outcome areas of the ECM framework (for more detailed information on results for different groups of children see Beresford et al. 2007; Rabiee et al. 2005a), and explores:

- How the components of these outcomes are described by disabled children and their parents.
- Whether the framework omits any aspects of disabled children's lives or aspirations.

## **Methods**

The study was carried out in three local authorities and worked with four groups of disabled children: children with autistic spectrum disorders (ASD)<sup>2</sup>, complex health needs (CHN)<sup>2</sup>, degenerative conditions (DC)<sup>2</sup> and children who do not use speech to communicate for physical or neurological reasons (NS)<sup>2</sup>.

Ethical approval was obtained from NHS research ethics committees.

### **Recruitment and sampling frame**

The study purposively sampled for ethnicity, gender and different levels of ability to take part in interviews, and to include approximately equal numbers of children in three age bands (0-6 years, 7-11 years, 12-18 years).

All families were approached via social services, education, health or voluntary organisations, who sent information to potential participants.

Children and young people were provided with an age appropriate written information leaflet, and/or leaflets containing symbols. Families interested in taking part returned a contact form to the researchers.

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<sup>2</sup> For brevity we will use these abbreviations for the four groups in the remainder of the text.

Ninety-five families took part in the project representing a total of 100 children (see Table 1). Ninety mothers and 18 fathers participated, including seven bereaved parents of children with DC. Joint interviews were carried out with both mother and father in thirteen families. Twenty-nine children participated directly. Where the child did not want or was not able to take part, permission was sought from the parent to speak to someone else who knew the child well in another context, such as a teacher or a non-parent carer, referred to as 'other informants'. Twenty-seven 'other informants' were interviewed. Discussions about friendships and transition of among a therapeutic group of 12 teenagers with ASD were recorded and included in the analysis. This was undertaken in order to supplement the data collected directly from children with ASD.

A range of socio-economic status and family composition was represented in the sample.

INSERT TABLE 1 ABOUT HERE

The children with CHN had a number of different impairments (typically cognitive and physical) and/or significant health conditions. Many of the children with NS also had complex health care needs. The degenerative conditions represented in the research included neuromuscular, neurological and metabolic conditions with limited life expectancy. The range of ASD was represented, including children with Asperger's syndrome. Care was taken to



ensure the groups were as distinct as possible though there was, inevitably, some overlap. All groups included children with a range of learning disabilities, from none to profound.

### **Data collection**

Semi-structured interviews were used to explore how disabled children and their parents defined their desired outcomes for their/their child's life.

Interviews with parents explored what they wanted for their child in all areas of their lives. A 'map' of the different areas of the child's life was used as a visual prompt, covering the following areas: health; activities and experiences; being at school; feelings and emotions; how the child feels about her/himself; relationships with family members, other children and other adults; communicating and being able to make choices; and becoming independent. Interviews with bereaved parents also asked about the nature and Circumstances around their child's death. Interviews with the 'other informants' were similar but limited to areas of the child's life they could comment on.

**Table 1 Families taking part in the research**

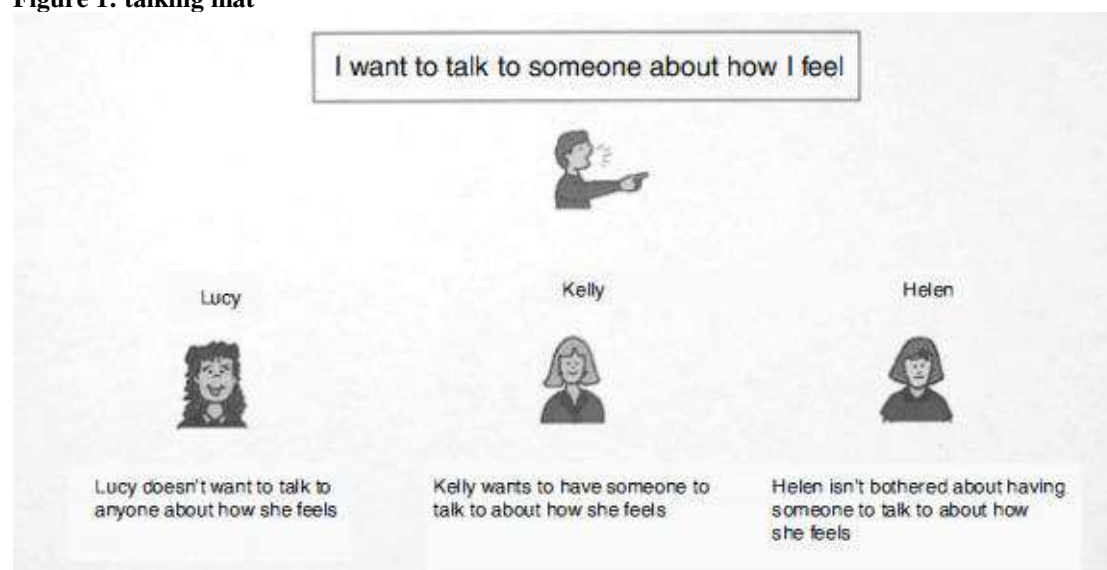
	Autistic spectrum disorders (ASD)	Complex healthcare needs (CHN)	Do not use speech (NS)	Degenerative conditions (DC)
Total no. families	25	26	24	20
Total no. children represented	28	26	24	22
Parental involvement				
Mother only	23	19	21	14
Father only	0	3	2	0
Mother and father	2	4	1	6
No. children involved directly	5	11	7	6
No. other informants	9	5	12	1
Age range of children (years)	5–9	2–18	3–18	2–18 (Bereaved families: 1–23)
Boys	22	10	13	10
Girls	6	16	11	12
No. minority ethnic group families	2	11	9	5

**Note:** Table excludes teenagers attending group observed as part of the fieldwork.

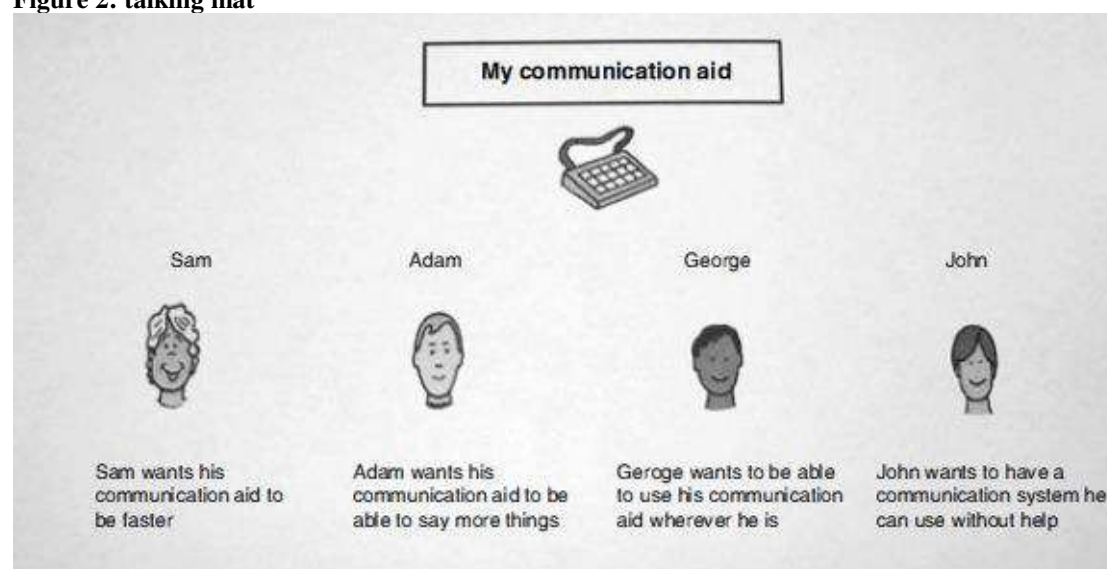
The methods used to promote children's participation are reported in detail elsewhere (Beresford et al., 2004; Rabiee et al., 2005b). Children who had good understanding and speech were interviewed first, using visual prompts and a 'map' of different aspects of the child's life. They were asked about positive and negative aspects of various areas of their lives and what they would like to change. Data from these interviews informed interviews for children who had limited understanding and/or who did not use speech. These interviews used the 'Talking Mats' approach (Murphy, 1998). This involved using A4 cards with the area of the child's life presented at the top of the card with accompanying symbol(s), and the lower part of the card representing opposing and ambivalent views (Figure 1), or different aspects of the overall area (Figure 2), using different characters. Statements were in simple

language and were read out to children, with explanation if needed. Children were asked which character's statement was most like them. The researcher made detailed notes of these interviews, paying attention to all methods children used to communicate.

**Figure 1: talking mat**



**Figure 2: talking mat**



All interviews covered aspirations for the present and near future, and children over 12 and their parents were asked about longer-term aspirations for adulthood.

### **Data analysis**

Interviews were tape-recorded and transcribed. The data were analysed by a process of data reduction and display, conclusion drawing and verification (Miles and Huberman, 1994). Three researchers each read a sub-sample of transcripts to identify a priori and emergent themes, and then agreed a framework for analysis, including categorisation of main and sub-themes. The data were then coded and drawn together using a computer assisted qualitative analysis package (Nvivo) and manual methods, and analysed to identify over-arching themes and conclusions. Conclusions were verified by checking with transcripts and on-going discussions within the research team.

The fieldwork and analysis took place before the development of the ECM framework, the researchers had no knowledge of this framework and themes were not linked to it (see Beresford et al., 2007; Rabiee et al., 2005a). The purpose of this paper is to summarise, across all groups of children, how the findings fit the ECM framework and to identify any omissions.

### **Results**

Like other children, many of the disabled children interviewed wanted to have friends and interests, to be part of the local community, to acquire social and

self-care skills and future independence, to feel confident and respected by others, and to experience success and achievement. Parents and other informants also wanted this for the children. However, there were certain important differences from the ECM framework. First, although the framework recognises the importance of communication for young children, this was important throughout the age range for many disabled children. Second, some aspects of an outcome for a disabled child could be very different to what that outcome would mean for a non-disabled child. Third, some outcomes were seen by parents and/or children as needing to be achieved before other outcomes could be achieved. We have called these 'fundamental outcomes', which were physical and emotional well-being, being able to communicate and staying safe. 'Higher level' outcomes were those which fell into the categories of enjoying and achieving, making a positive contribution, and economic well-being. Fourth, all outcomes include both progress or achievements and also maintenance, for example of physical functioning or a valued aspect of life. Where children experienced deterioration in their health and/or functioning, and maintaining a current level of functioning may not be possible, desired outcomes emphasised the importance of experiencing success and achievement at whatever level was appropriate for the child.

In addition, it was clear that children in particular, and to some extent parents, had most to say about outcomes in the category of 'enjoy and achieve'. One young person described how these issues were particularly important to her:

... these are the three things that I want to carry on through my life.....

Like my friends, I want to still have the same friends but have mixed

with other people, and my family, well they're the most, most important, I want them to be there for me, you know, when I'm older, and school, well education, that'll take me onto getting a job.

Child with CHN

## **Fundamental outcomes**

### *Physical and emotional well-being*

Physical well-being was crucial for all groups, but the emphasis on the dimensions of this differed between condition groups and, sometimes, from normative definitions of well-being. For many children with CHN and DC, being comfortable and not in pain was central to achievement of other outcomes.

When it's all spasming up and getting very hard, they more concentrate on their body let alone their schoolwork, they don't give two hoots about their school work....cos it hurts them, the spasms hurt.

Parent of child with CHN

For other children, maintaining health and functioning was seen by parents to be threatened by difficulties experienced in using health services (ASD) and problems with supply and availability in different settings of equipment (CHN and NS). For children with DC there was a tension between maintaining physical health and abilities against quality of life.

Emotional well-being was a key concern for parents of children with ASD, amongst whom many found it difficult to assess their child's emotional state.

....you can't learn how to spell and how to count unless you've first got your emotional health sorted out, and a lot of kids, special needs or otherwise, haven't got that, haven't got the base to start building upon. I would really love it if emotional help was the primary thing on the curriculum.

Parent of child with ASD

Making a positive adjustment to having a disability or health condition was something that parents across all condition groups highlighted. For children with DC, especially those who were able to understand the changes in their health and abilities, emotional support was needed for coping with these changes. Parents also emphasised the importance of meeting these children's emotional needs in the end stage, and ensuring the child did not feel anxious or abandoned.

### *Communication*

Being able to communicate was seen as fundamental to meeting desired outcomes in other areas of life for all groups. The nature of the desired outcome varied. For some parents of children, especially those with ASD, the desired outcome was hoping the child would want to communicate. For parents of children with severe learning difficulties and some of those with ASD, the desired outcome was for their child to be able to communicate basic needs. Children with good cognitive ability who, for physical reasons, could not speak, wanted to be able to communicate independently and have access to a communication system which gave them greatest opportunities to

communicate. One child told us that what she would want from a magic wand, more than anything else, is to have a computer that could help her talk to people. Children who already used a communication aid wanted it to be able to say more things and be faster.

Some parents of children with DC reported having to 'renew' their ways of communicating with their child as the condition caused degeneration of communication, physical and/or cognitive abilities. For example, means of communication may change from speech, to using communication aids, and then to hand squeezes, eye movements and facial expressions. The desire of these parents was that there would always be some way by which their child could communicate.

Both children and parents in all groups stressed the importance of everyone who had regular contact with the child having the knowledge and skills to understand the child's means of communication. Having the ability to communicate was seen as opening doors to more opportunities, such as socialising, being active and becoming more independent, which in turn help promote a child's feeling of security, confidence and self-esteem.

### *Staying safe*

Keeping children safe from exploitation and abusive relationships or physical danger, and the difficulties this poses when children receive care from a number of people, cannot communicate well or lack any sense of danger, was emphasised by parents in all groups.



She's very trusting though. She's got absolutely no sense of danger.

So that's a real worry for when she's older, and I don't know how you get round that one really.

Parent of child with ASD

Staying safe was also talked about in terms of preventing children having accidents. There were different reasons why a child might be vulnerable to accidents including using inappropriate or unsafe equipment, living in unsuitable housing and/or requiring high levels of supervision.

### **Higher level outcomes**

#### *Enjoying and achieving*

Enjoying and achieving encompassed various areas, each carrying different meanings for different groups of children:

*Socialising and having friends and relationships* was a priority for many children and parents. Children often looked happy and excited when talking about friends and this was clearly an important topic for them. For instance using the Talking Mats, a child who did not use speech chose the options of 'The most important thing about school is being with friends' and 'When she is not at school, she wants to go places where other young people go'.

However, friendship had different meaning for different children. For some children friendships meant equal relationships, sharing and exchanging views:

Good gossip, talk about loads of things...we share ideas, we listen to each other, we joke around...

### Child with CHN

For children with more severe cognitive impairment and communication difficulties having friends could mean, as described by a parent:

...being in a room with certain people because he likes those people,...he likes the fun they have and he can join in their fun, for me that is X having a friend, 'cause he can't say "...let's go and play football together", 'cause he can't interact in that way.

### Parent of child with NS

Parents of children with ASD, in particular those with severely affected children, recognised that to have friends their children would first have to desire to interact and learn social skills.

Across all groups, lack of contact with school friends out of school was seen as a barrier to achieving friendship. This was a source of considerable frustration for some children. All parents believed having friends inter-related to many other areas of the child's life, including taking part in activities, emotional well-being, and developing social and communication skills.

There often came a stage amongst the children with DC where interaction with peers was no longer a priority or appropriate, and the communication skills of people interacting with the child became more important. At all stages, skilled and loving contact and interaction was seen as fundamentally important to the child's well-being.

*Activities and experiences:* having interests and being able to participate in activities was something that all parents wanted for their child. Many were concerned that their child's 'world' was restricted to home and school. Most wanted their child to have greater variety and opportunities and to participate in mainstream activities in their local community. Similarly, many children expressed a desire to be 'doing more'. The lack of accessible or appropriate facilities and/or the lack of support to assist the child meant that taking part in mainstream activities was often very difficult.

Parents' views differed about the experiences they wanted their child to have. Parents of children with more severe impairments, and more limited ability to interact, often wanted their child to have opportunities to be with different people and experience different environments so that they would be kept alert as much as possible. Others wanted their children to have the same access to facilities as non-disabled children, and to have opportunities to go out, learn new skills, engage in age appropriate activities and have a break from family members. Accessing and enjoying everyday mainstream life for as long as possible, even though the child's condition was deteriorating, was important for children with DC. Parents highlighted the importance of finding new activities or sources of enjoyment when degeneration or failing health meant that previous pastimes were no longer appropriate or enjoyable.

*Education and learning:* All parents wanted their child to fulfil their learning potential. Parents of severely disabled children talked about learning in terms of their child enjoying a stimulating environment and working towards

achieving suitable goals. For those with limited cognitive abilities, acquiring self-care and living skills was often prioritised over academic achievements.

I want him to learn to dress himself, go to the toilet, feed himself, not the National Curriculum. I want him to be able to be as independent as possible and to my mind this [starting school] is the opportunity to do it.

Parent of child with ASD

However, for children with greater cognitive abilities, parents wanted their child to at least achieve basic skills such as reading, writing and number skills and to have knowledge (at some level) of the world they lived in.

Many children said that doing well at school was important to them. The majority of children liked school because it provided opportunities for learning, play and interaction with other children. For children in mainstream schools and their parents, having a good education was important as a route to future employment. Children with conditions that did not affect their cognitive abilities did not want their schoolwork to be affected by having to have time off (sometimes for weeks or months) due to ill-health or for treatments. Children with DC needed to have goals and achievements that were appropriate and responsive to the decline in their abilities. In some cases, the children needed help in adjusting their expectations for themselves in terms of academic achievements.

..it [pursuing the curriculum] was actually inappropriate....and it wasn't really meeting their need....Trying to develop this and improve that and make progress here but it just wasn't realistic because they [school]

didn't understand .. and they didn't want to offend us or upset us by admitting that actually they're not progressing.

Parent of children with DC

*Self-care skills:* for non-disabled children independence is often seen in terms of the child being able to do something without help. For many disabled children, for whom this degree of independence was not achievable in certain areas of their lives, independence was seen in terms of the child reaching their potential in their ability to carry out personal tasks and make choices as best as they can with or without support. This was a key priority among many children and parents across all groups. Some children said they could do some self-care tasks such as feeding and washing, but they wanted to do these things more independently. One child said: 'I think I might just need an electronic hoist so that I could do it [washing] myself'.

Achieving independence in self-care was seen by all parents to impact on other areas of child's life such as self-esteem. The extent to which children were independent in self-care varied according to the child's age and the severity of their condition. Among children with ASD who were independent in their self-care, parents identified more subtle achievements, such as choosing clean clothes, washing sufficiently frequently, and knowing what to wear.

*Life skills:* all parents wanted their child to become as independent as possible in their daily lives. Central to this was the acquisition of life skills, such as basic academic, communication and money skills, personal safety,

cooking, shopping, being able to go out alone and more generic skills such as making choices, interacting and dealing with people. The nature of the child's condition affected the ease or likelihood of achieving some or all of these skills. Independence was seen in terms of children reaching their potential in their ability to carry out life skills with or without support. Children described the life skills they wanted to acquire including: being able to make snacks, go out alone, go shopping independently, and understand and manage money.

*Identity and self-esteem:* for many children feeling 'normal' was important and was closely linked to being accepted by their peer group. 'Looking good', wearing similar clothes to others and being able to use attractive and acceptable equipment (for example boots, wheelchair) contributed to how they felt about themselves. One child's view of her wheelchair was:

It's too yucky, I don't like the colour... [it's] too horrible....

Child with CHN

Parents wanted services to be more sensitive to the child's identity and social integration when issuing equipment, making sure that it is attractive whilst offering appropriate support.

Parents wanted their children to feel that they were loved and that what they wanted mattered. Treating the child as an individual, involving the child in making decisions about his/her life, and respecting the child's privacy in a way appropriate to their age were said to help raise the child's self worth. Parents also thought that helping the children experience success by giving them achievement awards for things they have achieved at their own level would

boost their self-esteem and self-confidence.

He did gardening and loved it. He was star gardener. He's got pictures in the class of all his plants and we were very pleased with that because it gave him the confidence that he was good at things....

Parent of child with ASD

### *Making a positive contribution*

Disabled children were often marginalised in local communities. In order to make a contribution, they need to have the same access to opportunities and activities as non-disabled children. Being part of the local community was important to many children and parents across all groups. This might involve using adapted equipment or interpreting play at the child's level to make participation easier for the child. However, for children who attended special school, the location of the child's school and the inaccessibility of local facilities often meant that children did not participate in the local community based activities.

Being involved in and participating in decisions that affect children was important to many children and their parents. This included choices about what to wear, how and where they spent their time, planning for the future, and choices about their care and treatment.

### *Economic well-being*

Not all disabled children will be able to make an economic contribution and families with disabled children are more likely to be living in poverty than other

families, so the presence of adequate levels of benefits (during childhood and adulthood) was important.

In terms of future aspirations, having a job and earning money in adulthood was seen as important by young people who had good cognitive ability and their parents. Employment opportunities and support, and access to transport were seen as key factors in achieving these outcomes. Parents of young people with more limited understanding wanted their children to be meaningfully occupied and be able to contribute something, however small, when they become adults. Developing children's communication skills, including basic reading and writing skills where appropriate, was seen by parents across all groups to be a necessary step to facilitate that. For parents of children with more severe learning disabilities, who could not see their child being able to take on responsibilities, what mattered was to keep their child occupied and alert.

## **Discussion**

Overall, the research indicated that the ECM outcomes framework is relevant to disabled children. However, the level of achievement expected or desired in all outcomes, and priorities given to different aspirations, differed from normative developmental progress and between different children with the same condition, depending on the severity of the condition, age and, for some conditions, the way the condition manifested itself. Consequently normative, developmental models of outcomes are insufficient for disabled children.



There is a need to widen the definitions and indicators of key concepts in these frameworks to take account of disabled children's views and capabilities. In addition, as Qureshi (2001) found, it is important that an outcomes framework recognises that, sometimes, the goal is not progress but maintaining a particular level of physical functioning or ensuring a child can continue enjoying treasured aspects of their everyday lives. For example, among the children with degenerative conditions, the focus was often about maintaining quality of life when the child's abilities were decreasing and their needs and dependency increasing.

For some of the children in all groups, achieving full independence was not something they could aspire to. However, that does not necessarily indicate a poor outcome for those children; achievements need to be seen and celebrated within the context of the child's abilities and potential, and in some cases, their physical health. If the outcome indicators for ECM do not provide a means of valuing the achievement of disabled children, this will further compound their exclusion from the priorities of mainstream society.

### **Hierarchical structure and interdependence of outcomes**

As with Sinclair *et al.* (2002), the findings of this research indicate that outcomes have a hierarchical structure with strong interdependence between outcomes. Achievement of some outcomes depends on other outcomes that are fundamental for disabled children being met first. In this context, there is a significant omission from the ECM framework concerning the importance of communication across the whole age range. Whilst for non-disabled children

this is often taken for granted as they get older, it is a fundamental outcome at any age for children with communication impairments. Maximising a child's communication ability, and other people's ability to understand the child's means of communication, opens doors to opportunities to socialise and be active, and helps to ensure their basic physical, emotional and personal safety needs are met.

Similarly, there can be a hierarchical structure within a single outcomes category. This is illustrated by the role of pain in the 'being healthy' category. When children are in pain, it affects many areas of their lives. This applies to all children, but many disabled children are more likely to experience periods of pain because of their medical or physical condition, and are less likely to be able to express this. If interventions to minimise pain are not implemented, or are not successful, then other aspects of 'being healthy' are also at risk, as well as the extent to which outcomes in other areas of their lives can be achieved. The Children's National Service Framework advocates that children have a right to appropriate prevention and control of pain. Yet, assessment and management of pain in children is still underdeveloped (Joughin and Law, 2005).

### **Implications for services**

The interrelationships between the different outcomes and areas of the child's life highlight the need for multi-agency partnership. Areas such as friendship, skills acquisition, having opportunities to make choices and to take part in a variety of activities are not confined to one context and the support provided in

that context. Such interrelationships indicate that the same support can contribute to the achievement of different outcomes and similarly a lack of support in any one context can inhibit the achievement of more than one outcome. For example, inaccessible environments and/or lack of appropriate equipment were mentioned as important barriers impeding opportunities for socialising, being active, learning skills and promoting independence.

The interviews indicated that the achievement of many outcomes requires both specialist support *and* progress towards a more inclusive society so that disabled children are not denied opportunities available to non-disabled children. Similarly the impact of non-inclusive societal/peer culture is highlighted in children's aspirations around appearance and looking 'normal'.

Achieving many desired outcomes requires parents' support. Thus support for parents themselves to help them to assist their children in achieving their desired outcomes is important. Research has shown that parents with disabled children provide extra care, over and above that of 'the reasonable parent' (Roberts and Lawton, 2001), and it is with this extra care, and with learning the necessary skills to support their child's development and deal with any problems that arise, that they need support from services. While the role of parents is recognised within the strategy to achieve the ECM outcomes for children, the focus is mainly on support needed *from* parents, rather than the support parents need *themselves*.

### **Limitations of the study**

Both a strength and a limitation of the study is the involvement of children.

Whilst we were able to obtain the views of a range of children, and the methods used proved encouraging in facilitating communication with children who did not use speech, involvement of some groups was very limited: these included children with ASD, especially those with more severe levels of impairment, and children with severe cognitive impairments. Obstacles to the involvement of these groups are difficult to overcome. Abstract and future issues central to the concepts of desires, aspirations and outcomes have little meaning for some of these children because of limitations of their cognition. The approach taken in the project was to ascertain what children liked and valued in their lives and, if possible, what they would like to change. Whilst this was largely successful, the information was limited by the amount of time we were able to spend with the children. Two visits were undertaken with each family, first an interview with the parent(s) during which the child's communication needs were discussed and, if possible, the researcher met the child, and second an interview with the child. In most cases, this interview took place on one occasion only. However, it is likely that with repeat visits (not possible within the resources of the project) it would have been possible to build up a fuller picture of children's views.

Disabled children are not a homogeneous group, and in this project we chose to focus on certain groups of children who are often seen as 'hard to reach' and as causing concerns for service providers. This means that the results of the research do not necessarily apply to other groups who were not part of the project. Children with special educational needs, such as children with

moderate learning disabilities or emotional and behavioural difficulties, may have different views on the outcomes they aspire and prioritise.

## References

Axford N, Berry V. 2005. Measuring outcomes in the 'new' children's services. *Journal of Integrated Care* 13: 12-23.

Beresford B, Tozer R, Rabiee P, Sloper P. 2004. Developing an approach to involving children with autistic spectrum disorders in a social care research project. *British Journal of Learning Disabilities* 32: 180-185.

Beresford B, Tozer R, Rabiee P, Sloper P. 2007. Desired outcomes for children and adolescents with autistic spectrum disorders. *Children and Society* 21: 4-16.

Connors, C. and Stalker, K., (2003) *The Views and Experiences of Disabled Children and their Siblings: A Positive Outlook*. Jessica Kingsley: London.

Department for Education and Skills. 2003. *Every Child Matters*. DfES Publications: Nottingham.

Department of Health. 2001. *Framework for the Assessment of Children in Need and their Families*. Department of Health: London.

Department of Health/Department for Education and Skills. 2004. *National Service Framework for Children, Young People and Maternity Services*. Department of Health: London.

Joughin C, Law C. 2005. *Evidence to Inform the National Service Framework for Children, Young People and Maternity Services*. Department of Health: London.

Miles M, Huberman A. 1994. *Qualitative Data Analysis: An Expanded Source Book*. Thousand Oaks, CA: Sage.

Murphy J. 1998. Talking mats: Speech and language research in practice. *Speech and Language Therapy in Practice* 11-14.

Qureshi H. (ed.) 2001. *Outcomes in Social Care Practice, Number Seven*. Social Policy Research Unit, University of York: York.

Rabiee P, Sloper P, Beresford B. 2005a. Desired outcomes for children with complex health care needs and children who do not use speech for communication. *Health and Social Care in the Community* 13: 478-487.

Rabiee P, Sloper P, Beresford B. 2005b. Doing research with children and young people who do not use speech for communication. *Children and Society* 19: 385-396.

Roberts K, Lawton D. 2001. Acknowledging the extra care parents give their disabled children. *Child: Care, Health and Development* 27: 307-319.

Sinclair R, Cronin K, Lanyon C, Stone V, Hulusi A. 2002. *Aim High, Stay Real. Outcomes for Children and Young People. The Views of Children, Parents and Practitioners*. Children and Young People's Unit: London.

Turner, C. (2003) *Are You Listening? What Disabled Children and Young People in Wales Think about the Services They Use: A Consultation to Inform the Children and Young People's National Service Framework*. Barnardo's Cymru: Cardiff.